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ABSTRACT

This report on Community Vision, Inc. is part of a series documenting innovative supports for community living for adults with severe disabilities. Community Vision was created as an alternative to facility-based services in Oregon that would intentionally focus on providing inclusive community living for those with the most severe disabilities who were still in institutions, nursing homes, and other facilities. The agency currently supports 45 adults in community living, jobs, social relationships, and other community activities. The report is based on a site visit to the agency in August 2000 that included interviews and visits with people who are supported by Community Vision, family members, and agency staff and administrators. The lessons the agency has gained from direct experience of supporting individuals with severe disabilities in the community in Oregon contribute to the agency's key strengths, which include a focus on promoting a sense of home, personal control and choice; relationships, work, and meaningful community involvement for the people the agency supports; and an organizational focus on planning and teamwork/collaboration. These combined strengths are discussed, along with examples of how individuals are supported. Challenges facing Community Vision, Inc. are also discussed. (CR)

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COMMUNITY FOR ALL IS POSSIBLE:

PROMOTING HOME AND COMMUNITY

LIFE AT COMMUNITY VISION, INC.

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AT COMMUNITY VISION, INC.

Pam Walker

May 2001

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Introduction

Community Vision, a support agency in Portland, Oregon, began in 1989 in response to the need of one person. The director had previously worked in agencies that operated more traditional services such as group homes and "semi-independent living" settings. Then, in the mid- to late-1980s, he worked to help a local agency close its group homes and develop more individualized services, with the assistance of national consultants who had expertise in this area. After this experience, he decided to work as a consultant within Oregon developing community supports for people with severe and multiple disabilities. In this capacity, he was contacted by a family who asked for his assistance in helping their son, Phillip, move back home with them from an institution. Phillip had a rare, progressive neurological disorder, "Battens Disease." His older sister, Elizabeth, also had Battens Disease, and the family had previously fought to have her come home from a nursing home. Phillip was able to move back home and lived there until his death in 1992. This experience of supporting Phillip and his family led, eventually, to the creation of Community Vision, an agency aimed at extending the vision of Phillip and his family to include others with the most severe disabilities.

At the time when Community Vision started, most other agencies in the area offered group homes and other facility-based supports. There was a growing demand for alternatives, as well as growing pressure to close the institution. There were many in the system and beyond

who still believed that some people, particularly those with the most severe disabilities or challenging behaviors, needed some type of facility-based care; as a result, for example, more people with developmental disabilities were ending up in nursing homes. Thus, Community Vision was created as an alternative to facility-based services that would intentionally focus on providing inclusive community living for those with the most severe disabilities who were still in institutions, nursing homes, and other facilities. The agency currently supports 45 adults in community living, jobs, social relationships, and other community activities. For many people they support, agency staff have assisted in the transition from institution or nursing home to community life. Some people have support 24 hours a day, including a live-in housemate and other staff who provide support during the week days and weekend for jobs, volunteer work, and other community activities; other people receive a few or several hours a day of support.

This report on Community Vision, Inc. is part of a series of reports from the Center on Human Policy documenting innovative supports for community living for adults with severe disabilities. It is based on a site visit to the agency in August 2000 which included interviews and visits with people who are supported by Community Vision, family members, and agency staff and administrators. It reflects the agency and the people who are supported by Community Vision at that point in time.

The lessons the agency has gained from their direct experience of supporting Phillip and others with severe disabilities in the community in Oregon, as well as from contact with other agencies across the country that also support people with severe disabilities in community living, contribute to the key strengths of the agency. These include a focus on promoting a sense of home, personal control and choice, relationships, and work and meaningful community involvements for people who they support; and an organizational focus on planning and

teamwork/collaboration. These combined strengths underpin the agency's efforts to implement a vision of home and community life for all; they are discussed in the next section. This is followed by a discussion of some of the challenges facing Community Vision, Inc. in implementing its vision.

A Home and Community Life for All

Based upon their experience supporting people in community life, agency staff have learned that some of the most important aspects of this include having a sense of home; personal control and choice; relationships, particularly those that are nonpaid; and work and/or other meaningful pursuits.

Sense of Home

Community Vision was inspired by Phillip's clarity about wanting to living in a home, rather than a group home. As he put it, "If you move me to a group home I'll bust everything to pieces." Community Vision supports people who rent and own their own homes, who live in houses and apartments, and who live alone and with others. Currently, six people own their own homes. Whatever the situation, staff place priority on assisting people to have a sense of home, including stability, security, and personal control.

Robert is one of the people who owns his own home. He is 47 years old, has cerebral palsy, and lived in an institution for 30 years. Because of some past issues with personal boundaries, if he were not being supported by Community Vision, it is the opinion of agency staff that he would likely be living in a locked facility. In order to address the boundary issues, the agency provides 24-hour support for Robert. This includes a housemate who supports him

during the evenings and overnight, and two others who support him during the daytimes and weekends. Even with this level of support, the cost for his services is only about $5,000 per month, compared to about $20,000 a month in an institution.

After leaving the institution, he first lived in an apartment, then rented a house. Finally, in 1997, with the support of Community Vision, he bought his own home. Staff helped him in an extensive search for a home he could afford in a neighborhood that he liked. It is a quiet residential street with small houses on the outskirts of the city. He lives there with his dog, Max. He has gotten to know some of his neighbors, who assisted in laying the sod for his front lawn and in putting up a fence for Max. Overall, Robert is very pleased with his house and the support he receives, and much prefers it to life in the institution.

Personal Control and Choice

Staff at Community Vision believe that personal control and choice are central to a quality life in the community, and that they are particularly important for people labeled with the most severe disabilities and the most challenging behaviors. This includes control and choice across all aspects of their lives, including where and with whom they live, who provides support, relationships, work and pursuit of other interests, and so forth. They recognize that the people they support, many of whom have lived in institutions and other facilities for many years, have had very little control and choice in their lives and that exercising control and choice is a process, not a one-time event. For example, as one staff person commented, "When people move from the institution, often, the first place they live is a starting place, and they may decide after that they want something else." At first, people often choose a place that is near to family, or near to where they work, go to church, or to other familiar community places. Over time, people move

based on new opportunities or choices. Staff also recognize that, even if they are at first not sure what choices the person would like to make, if they spend enough ongoing time listening to the person, these will become more clear.

Sophie is one person the agency has supported to gain significant control over her life, as she moved from a nursing home into her own home. Sophie, who has severe cerebral palsy, lived at home with her mother until her mother was no longer able to lift Sophie and provide care for her. Sophie ended up in a nursing home, where she spent 14 years. Eventually, her mother ended up in the same nursing home. At a time when the state was making efforts to assist people with developmental disabilities to move out of nursing homes, Sophie was referred to Community Vision. Her mother did not want her to leave, but Sophie was determined to move out. During initial planning with agency staff and others, she decided she wanted to marry Henry, who she knew from a sheltered workshop that they both worked in, and move into a house with him. After a few years, Henry and Sophie decided to separate, and Sophie began a search for a new house, with the assistance of Community Vision. She decided on a small house on the outskirts of the city. She rents the house for $300 a month, most of which is covered by a housing certificate. She likes being in a quiet neighborhood, which is nice for her cat as well, and she has gotten to know some of the neighbors, who often stop by to visit. Sophie works at a coffee shop two days a week. She enjoys going to the weekly farmers' market, movies, and other community events. She also enjoys regular visits from her sister and brothers, who live nearly.

While Sophie is very happy to be here, she recognizes the trade-offs she made in this choice--that it is difficult for her to get around her neighborhood due to the gravel roads; and that transportation to visit friends and participate in other aspects of community life is difficult in this location. While it is clear that Sophie likes many things about this house, it is not clear if she

will stay here for the long term, or chose another location. Staff at Community Vision would assist in seeking an alternative place to live if she decides to do so. However, they are also working with her to enhance her life in this location. For example, a community business recently donated materials and time to help her build a large, accessible patio, and she is saving some of her money toward the possible purchase of a van.

Relationships

Staff at Community Vision believe that relationships are an essential aspect of community life. They believe that "support" is not just about activities, but that it is equally about presence, relationships, and interconnections. Thus, a major focus for staff is on the development of positive relationships with those they support. In addition, they feel that it is also a critical for people to have nonpaid, community relationships. Staff support this in multiple ways, such as assisting people to develop and/or maintain relationships with family members and co-workers, and to get to know neighbors and other community members through regular participation in neighborhood and community life.

Pete is 45 and lived in the institution for 33 years. When the institution was closing and it was clear he would have to move, Pete's parents indicated that they would prefer that he live in his own home, rather than a group home. They began planning with staff from Community Vision while Pete was still in the institution. After several months of planning, in 1998, Pete moved from the institution into his own home, which he rents. Pete receives support from three primary people--one who lives with him and provides support from 5:00pm until 9:00am, Sunday through Thursday; another who assists him during the weekdays; and a third who is with him on weekends.

Staff have placed priority on building trusting, positive relationships with Pete. It is on the basis of these relationships that they have learned how to best support him. As one staff person commented, "They way underestimated Pete and his abilities at the institution. The big thing I've learned, I thought at first he was so limited, but then I realized he understands everything; when he doesn't he asks for help." Over time, some of Pete's relationships with staff have grown to extend beyond "work"; for example, Pete has become close to the family of one staff person, and occasionally joins them for holidays and celebrations.

Staff also make efforts to promote nonpaid relationships for Pete. For instance, this includes supporting his relationships with his family, and helping them feel welcome at Pete's home. Pete has close relationships with his mother and brother. After being in favor of the move but at the same time apprehensive, Pete's mother shared her feelings about his life now: "Pete's very happy. You always have fears, but it's worked out real well." Pete also enjoys friendly relationships with neighbors, and is known in the community through his work, his regular use of neighborhood places, and his participation in neighborhood and community events. With the assistance of support staff, he regularly does shopping, banking, and other errands in his neighborhood. In addition, he enjoys hiking, baseball games, and participation in other community activities.

Overall, staff at the agency feel that relationships that people have with staff and with others in the community have been critical to positive community experiences. As the director observed, "Most of the time, when the best things are happening for people, it's due to relationships." They feel that it is people's relationships that have helped them through crises, and have prevented the agency's use of facility placements, as is sometimes done in other agencies. Staff regularly use input from other staff on their team and the agency as a whole in

order to generate ideas to promote increased community connections for people they support; when they have had particular difficulty helping someone make community connections, they have used help from outside consultants to assist in thinking and strategizing about this.

Work and Other Meaningful Community Involvements

Community Vision provides support for employment and other daytime pursuits to 34 people (20 of these people also receive supported living services from the agency). The agency supports people in a wide variety of jobs and other activities. For example, Robert has a part-time paid job at a supermarket; in addition, he does volunteer work at the Humane Society. Pete operates his own recycling business, with the assistance of a job coach; the business has grown so much that Pete now employs another person in his business. From the proceeds of his business, he enjoys giving back to the community; for example, he has donated recycled paper to children at a local elementary school. At Pete's home, plans are in place to build a workbench, so he can better pursue his love of woodworking. Another young man, Derrick, is receiving support in working toward his GED and in working on computers at the local community college. In his spare time, he enjoys athletics, such as swimming, basketball, and weight lifting.

Staff at the agency acknowledge limitations in helping to create meaningful daytimes for all of the people they support--for instance, they have struggled to find meaningful activities for some people who have difficulty communicating some of their preferences; and they have struggled to support regular participation in community activities for some people due to challenging behaviors. However, a strength is that agency staff are persistently working to address these issues. In addition, overall, a strength is the agency's focus on a wide variety of

work situations including self-employment, as well as on multiple other types of daytime activities and community connections.

While this section has addressed some of the components of home and community life that are emphasized at Community Vision, the following section describes some of the ways that the agency approaches these.

Organizing to Support Home and Community Life for All

Two of the central ways that Community Vision is able to support people and families with complex needs is through extensive planning and collaboration. Each is discussed briefly below.

Planning with People

Planning is a central component of support, and over the years staff at Community Vision have gained significant experience and knowledge about planning in ways that facilitate transition to the community for those who have spent many years in institutions and may have been cut off from family and other community connections and experiences. For all those who are supported by Community Vision, this begins with approximately 3 months of planning, sometimes more. The planning involves initial extensive communication and interaction with the person, family, and/or others who know the person well; this beginning work of establishing positive, trusting relationships lays the foundation that will help them share concerns and resolve disagreements in their ongoing work together. During the planning stages, there may be mixed feelings among those who participate in the process. For instance, in planning with Phillip and

his family, the director of Community Vision emphasized, "It was important to acknowledge feelings of both elation and panic."

Several months were spent by a team of people, including Molly, her family, agency staff, and consultants, in planning for Molly's move from the institution to the community. This included numerous visits and meetings with Molly at the institution. Due to Molly's intensely destructive behaviors, she was one of the last people to leave the institution, where she had lived for 30 of her 40 years. During planning, the team worked with Molly and her family to identify where she would like to live. Things that were important included a house with a large yard and a park nearby. Planning included physical preparation of the house, such as putting protective shields on the windows. In addition, initial support arrangements were decided upon. These include a support person who is awake at night (11:00pm to 9:00am), a community facilitator during the day from 9:00 to 5:00, and a vocational support person from 1:00pm to 5:00. These two daytime supporters often work together to assist Molly in the community. Finally, a behavioral consultant who uses a person-centered, positive approach was engaged for planning as well as ongoing assistance after Molly's move to the community. Overall, this makes Molly one of the most expensive people supported by Community Vision, at about $12,000 per month, which is still significantly less than the rate in the institution.

The team is still struggling to find community activities that are interesting to Molly; and she still engages in some destructive behaviors. In light of this, staff at Community Vision sometimes feel frustrated at their ability to support her. However, Molly's family, who visits twice a month, are reportedly "thrilled" with the change in her life.

Overall, as the agency plans with people, some of the key aspects to this include:

- Focus is not on disability labels. Rather, they emphasize getting to know people and focusing on their strengths, capabilities, and interests.
- They realize that the agency is not for everyone. Sometimes during the course of planning it becomes evident that there is not a good match between what the person wants and what the agency can offer. Thus, instead of trying to fit everybody in, they work with the awareness that the agency is not necessarily best for everyone.
- A third aspect of planning is that plans are not set in stone; rather, they form the basis for a starting point in the community, from which initial plans may be changed or altered depending on the individual's evolving needs and desires.
- Finally, in initial and ongoing planning, realistic constraints on resources are taken into account. At the same time, agency staff are creative in raising money or finding community resources.

Teamwork and Collaboration

Staff at Community Vision see collaboration (e.g., with people with disabilities, families, community members, consultants) as key to their success, particularly in supporting those people who present the most challenges to them. For example, figuring out how to effectively support Derrick has necessitated a focus on close collaboration among staff themselves, with Derrick and his family, and with various consultants. In the past, Derrick's modes of behavior and communication have challenged numerous agencies within the state of Oregon and beyond; he has some behaviors that are potentially harmful to himself and others, he sometimes has run away, and he has limited verbal communication. At one point, he was placed back in the

institution by a community service agency at a time when, according to the director of Community Vision, "no one was going back to the institution." After his family's lack of success in finding appropriate, quality supports for Derrick in Oregon, he eventually ended up in a program in another state. However, this was not an optimal situation either, and due to his family's continued search for something that was better for Derrick and closer to home, the Oregon state director of services for people with developmental disabilities contacted Community Vision to see if they would support him. In order to begin getting to know him before he moved back, the director and a few other staff members traveled a few times to meet with him.

Derrick has been back in Portland since 1997. At first, he moved into an apartment, but after awhile, it became clear that more space would be preferable. Staff at Community Vision worked with Derrick and his family to find a small house in a residential neighborhood. It is near a church, which was one of Derrick's priorities. Derrick is athletic and enjoys swimming, basketball, and lifting weights. He also has been working toward his GED, and he enjoys working at the computer lab at a local community college. He spends time with his family three days a week. Although Derrick enjoys a variety of activities and interests, his behaviors sometimes get in the way of doing these things.

Derrick has a housemate who lives with him, two supporters who assist during the weekdays (one who assists with community activities and another who supports this person and coordinates medical and other services as well as communication between all those who are involved with him), and another who provides support on the weekends. Derrick's labels include autism, Tourette syndrome, and obsessive-compulsive disorder. Community Vision's support of Derrick has involved close work with local and national consultants for positive behavioral

supports. Addressing all of these issues has necessitated close collaboration between many different people. While these efforts have met with some success, finding the right combination of ways to support Derrick in the best quality of life possible has also been an ongoing challenge.

In general, although Derrick has his ups and downs, he seems happy with his home and his support staff. In addition, although Derrick's family are sometimes still frustrated by the difficulties that he still has, overall they feel that his life is much better now than before and they are very pleased with the working relationship that they have with agency staff.

Overall, as previously noted, the ways in which agency staff collaborate with one another, and with those beyond the agency, are key to supporting people with severe disabilities. Within the agency, efforts are made to recruit housemates and other support staff who are willing to work as a team. As one staff member emphasized, "In working on a team, and supporting people, flexibility is one of the most important things." The agency uses resources such as colleges and universities, shared housing groups or services, churches, and other community groups for staff recruitment. Staff are organized into teams; these teams are particularly useful to staff in helping them get beyond the day-to-day issues. For effective teamwork, it is also important that staff feel like they are an integral, valued part of the team. One aspect of this is the efforts that are made by Community Vision to pass along the vision and enthusiasm about implementation of this vision to all staff. In addition, it is important that the agency attempts to provide reasonable pay and benefits, and to support the staff in other ways. For instance, at one time, at the request of people who are housemates, the agency convened a group for them to share ideas and give support one another. In general, staff seem to feel supported, and this is reflected in the significant number of long-term staff at Community Vision.

In relation to the people whom they support, collaboration is seen not as an alternative to personal choice and control, but as a context within which individuals can best be supported to increase their personal choice and control, without feeling as though this is taking place in isolation. And, in terms of collaboration with families, the agency has significant success in working with families within complex and sometimes very challenging situations. This success is, in part, based on their understanding of the past experiences of families which can make collaboration difficult. As one staff person commented, "We need to understand they may have had a long history of struggle, so it can take a long time to build trust." Despite the challenges, agency staff have a commitment to stand with families, over the long haul, through both the frustrations and challenges as well as satisfactions and successes of collaboration.

Finally, as described above, the agency collaborates with a variety of consultants at a local, statewide, and national level on issues ranging from the needs of a particular individual to those related to the agency as a whole. In addition, over the years, the agency has cultivated positive, collaborative relationships with county and state developmental disability representatives, as well as with members of other community groups and organizations. All of these various types of collaborative relationships have benefited the agency and individuals supported by the agency in a multitude of ways.

Challenges

In supporting people with severe disabilities in individualized ways in the community, there are a number of challenges and struggles facing Community Vision that are common to other agencies that are engaged in similar efforts. This section does not attempt to present a comprehensive listing of all of the challenges, but instead focuses on two key issues: creating a

sense of home for people who require 24-hour support and maintaining staff and organizational energy in ongoing work to promote individual inclusion and systems change.

Creating a sense of home for people who need 24-hour support. It has been challenging for many agencies to figure out how to provide 24-hour support to those who need it in a way that promotes a sense of home, rather than a facility-like atmosphere of shift staffing and other routinized schedules and arrangements. In order to do this, many agencies, including Community Vision, have used live-in housemates, who typically provide support in the evening and overnight, while other agency staff provide support during the day. While there are generally many positive aspects to such arrangements, there are also certain challenges associated with them. One is that the housemates are typically not agency staff, and thus it may be more difficult for them to feel connected to and supported by the agency as a whole. It is positive that, as previously mentioned, Community Vision has been responsive to housemates' request for informal group time together. In addition, the agency makes significant efforts to accommodate housemates when they need time off for a family crisis or other reason.

Second is the degree to which housemates themselves have a sense of home and community connections. This may be different in each situation, but attention must be paid to the potential impact this can have on the person and the home environment (e.g., household routines, decisions, interactions, and so forth). In order to address issues related to this, the agency has used lessons from past experiences with housemates to better recruit others. For instance, they found that housemates who have some active interests and social networks work out better than those who are more isolated and inactive.

Maintaining staff and organizational energy for ongoing work to promote individual inclusion and systems change. On an individual level, sometimes, after a lot of time and effort

on the part of Community Vision, families, and others, it still seems as though the agency is struggling to find the best ways to positively support a person. In these situations, it is helpful for them to get the perspectives of others outside the agency, who both offer new ideas and can sometimes recognize positive changes that are not evident to agency staff who have been so closely involved in the situation.

In addition, based on their experience over the years, even when things are going well for a person, staff at Community Vision are aware of the vulnerability of individuals to a change in circumstances that can have a significant impact on their lives. For example, they recognize that staff can be key to people's connections with others, and when those staff people leave, some of the connections may fall apart. In order to address this, they work to have a team of staff who know people well, rather than just one or a few people. And, overall, it is a testament to the agency's commitment to their mission that they have been willing to enter into some complex situations that others have not been willing or able to address.

On the systems level, staff at Community Vision have a number of concerns. They are troubled by the poverty of people they support and of the staff who provide direct support to them. They also have concerns about both the amount of bureaucratic paperwork, as well as the ways it detracts from devoting time and energy to the issues that are most important to people's quality of life. Finally, they express frustration that after so much experience within Oregon and nationwide illustrating that all people can be supported in the community, there is still so much time and energy needed to confront the system's bias toward facility-based, congregate services.

Conclusion

Across the country, increasing numbers of agencies are supporting some people with severe disabilities in individualized, creative ways. At the same time, many of these agencies also still use some forms of congregate, facility-based supports, and it is still somewhat unusual to find agencies that are providing person-centered supports on a routine basis for people with the most severe disabilities.

Inspired by the persistence of Phillip and his family, staff at Community Vision have a passionate commitment to carry this vision forward, making community living possible for all. Without their commitment to this vision, many if not all of those who are supported by the agency would be in group homes, nursing homes, or other facilities. The agency's implementation of this vision focuses on assisting people to create a sense of home, personal control and choice, relationships, and meaningful work and other pursuits, within a context in which there is both planning that incorporates flexibility, and collaboration that supports increased control and choice. In addition, implementation of this vision has necessitated ongoing examination of agency policy and practices in relation to the vision, intentional efforts to pass the vision along to all staff and associates of the agency as well as members of the community as a whole, and continual reconnection of the vision to the real lives of real people. Phillip's life and death serve as a reminder that this vision can and does apply to all people, and as a reminder of the urgency to implement this vision now.